

Review of the Process for Developing Recommendations

Rohini Khillan

Office of Disability, Aging, and Long-Term Care Policy
HHS Office of the Assistant Secretary for Planning and
Evaluation

ASPE.hhs.gov

1

2015 Recommendations

- ▶ Compiled by the three subcommittees (Research, Clinical Care, and Long-Term Services and Supports) during their meetings in between larger Council meetings
- ▶ Recommendations were voted on by all the non-federal members at the January 2015 Meeting
- ▶ Subcommittee chairs wrote a brief overview as an introduction, Ron provided a cover letter
- ▶ Recommendations were sent to the Secretary and Congress in late February

2

Recommendations vs. Plan

- ▶ Recommendations are the issues and gaps identified by the non-federal members of the Council that they think should be addressed
- ▶ The National Plan is the government's yearly progress report on what federal agencies have accomplished on dementia
- ▶ If there are Recommendations made by the Council that can be addressed by the federal agencies, they become action items in the National Plan

3

Research Recommendation #1

The 2015 National Plan must provide a robust, comprehensive, and transformative scientific roadmap for achieving the goal of preventing and effectively treating Alzheimer's Disease by 2025.

- Roadmap should invite broad and inclusive input from experts
- Priorities and interim milestones should be evaluated and updated each year
- Include specific research milestones to:
 - Reduce racial/ethnic/socioeconomic disparities in AD
 - Increase access to early diagnosis, diagnostic procedures, and potential disease modifying treatments among diverse groups
 - Make significant improvements in research recruitment rates and outreach among diverse populations
- Include and prioritize specific milestones for Alzheimer's Disease Related Disorders
- Include and prioritize specific milestones for populations at high risk for AD (e.g., people with Down Syndrome)

4

Research Recommendation #2

The urgent need for increased annual federal research funding sufficient to meet the 2025 goal remains a top priority.

- Initial estimates of that level are \$2 billion per year but may be more. This investment would be applied to Alzheimer's research initiatives spanning basic, translational and clinical research

5

Research Recommendation #3

In developing their professional judgment budget, the NIH should identify the total science-driven funding needs for the budget year and also address the scale of needs anticipated through 2025.

6

Research Recommendation #4

The 2015 National Plan should outline specific contributions being made by the US government to the international initiatives needed to fulfill the commitments made by the US Government at the 2013 Dementia Summit in London

- This includes how the US Government intends to raise the level of engagement, and seniority of governmental officials, engaged in those efforts

7

Clinical Recommendation #1

Dementia Friendly Communities

- ▶ *HHS should encourage efforts to foster Dementia Friendly Communities*
 - A Dementia Friendly Community (DFC) resource currently exists on a state basis in Minnesota (Act on Alzheimer's), which has enabled 33 communities to start local efforts to better support people living with dementia and their care partners.
 - Early results from this effort has shown increased awareness of dementia throughout all sectors of the community (law enforcement, businesses, transportation, faith communities, etc.) as well as increased options for care partner support and engagement with the community.
 - HHS should support a piloting process of 10-15 communities or states funded by an RFP process that would help seed community efforts and evaluate results. The communities chosen should reflect differences in cultural groups, size of community, and rural/urban locales.
 - Should the evaluation of the pilot programs justify replication, then the goal would be widespread adoption of Dementia Friendly Communities by 2020.

8

Clinical Recommendation #2

Improving Clinical Care for Persons Living with Dementia

- *Evaluate feasibility of measuring care quality and effectiveness by using patient centered goals*
- HHS should identify measures currently available that would reflect patient perspectives on care satisfaction in various settings.
- Initiate regular measurement and reporting with those that are feasible now and,
- Develop a specific plan to improve measurement capability over the next 3 years so that the perspectives and goals of persons with Alzheimer's and their families are known. Subsequently, the metrics/goals relating to satisfaction with care and timely diagnosis can be developed and also measured.

9

Clinical Recommendation #3

Ensuring the Quality Of Life And Quality of Care for Persons Living with Advanced Dementia and Their Families Across Care Settings

- ▶ Ensure access to high quality palliative care for persons with advanced dementia and their families across all settings
- ▶ Prepare a workforce that is competent to deliver care to persons with advanced dementia and their families
- ▶ Incentivize documentation and tracking of level of functional and cognitive status to identify people with advanced dementia
- ▶ Support research, evaluation and dissemination of models of care to meet the needs of persons with advanced dementia and their families
- ▶ Leverage existing mechanisms to ensure access to high quality care for persons with advanced dementia and their families
- ▶ Support quality metrics that ensure transparency and accountability for the care of persons with advanced dementia and their families

10

LTSS Recommendation #1

Dementia–Capable Long–Term Services And Supports

- ▶ *The Department of Health and Human Services (HHS) should support state initiatives to provide robust, dementia capable long-term services and supports systems through:*
 - Providing coordinated Alzheimer’s disease related activities across state agencies through an identified state lead entity with adequate funding from Congress
 - Supporting Alzheimer’s Advisory Council partnerships with national partners to engage state governments in long-term services and supports efforts
 - Partnering with state lead entities to assure full access to long-term services and supports for populations at high-risk for Alzheimer’s disease

11

LTSS Recommendation #2

Long–Term Services And Supports Research and Evaluation

- ▶ *HHS should encourage federal agencies to include research on long-term services and supports that addresses dementia capability in their research agendas. Topics needing further research include:*
 - Interventions that are: Culturally appropriate, for persons in the early stages of dementia, for persons with Down syndrome and other intellectual disabilities, and for persons in the end stages of dementia.
 - Impact of caregiving on health and quality of life of caregivers.
 - Adequate training for paraprofessional caregivers in every venue to address cultural and dementia competence.

12

LTSS Recommendation #3

Coverage

- ▶ *CMS should redesign Medicare coverage and health care providers' reimbursement to encourage diagnosis, support care planning, and active referral to long-term services and supports:*
 - Include care planning with a family caregiver in Medicare coverage even if the individual with Alzheimer's disease is not present
 - Incorporate recommendations for palliative care into CMS surveillance and quality improvement systems
 - Provide reimbursement for providers to discuss palliative care early in the disease process

13

LTSS Recommendation #4

Caregiver Support

- ▶ *HHS, state lead entities, and providers should assure that caregiver health and behavioral health risk is assessed and addressed regularly through:*
 - Engaging individuals and families in advance care planning (health, legal, estate, and financial).
 - Assuring that health and related systems funded with federal resources improve chronic disease treatment and related services for people with Alzheimer's disease as well as family caregivers.

14

LTSS Recommendation #5

Funding for Long-Term Services And Supports

- ▶ *Congress should assure adequate funding for the following:*
 - Activities listed in the Public Health Roadmap, the Alzheimer's Disease Supportive Services Program (ADSSP) and the National Family Caregiver Support Program.
 - The Older Americans Act Title III to expand services to people with younger-onset dementia.
 - The cost of federal support for state lead entities is estimated at \$80 million. Cost of other recommendations should be calculated by public and private entities with resources to establish estimates.
 - An HHS panel to recommend innovative means of financing long-term services and supports.

15

Ideas for improving future collaboration on recommendations

- ▶ Need to have more communication and collaboration across federal, state, local and private sectors
- ▶ Continue to be focused and clear – Succinct is most helpful to the intended audience
- ▶ Categorization:
 - Funding (Congress)
 - Policy change (changes or refocus of existing programs, HHS-level)
 - Legislative change (Congress)
 - Suggestions for states/localities to pursue (increases National focus)
 - Private Sector work
- ▶ Appendix in the Plan containing recommendations and the Federal response

16

Using the Subcommittees

- ▶ In the lead-up to the vote on recommendations in April, we can spend time in subcommittee meetings discussing recommendations collaboratively (feds and non-feds)
 - Identify the issues
 - Identify barriers and challenges
 - Proposed ways to move forward
- ▶ The results of these discussions can be presented in subsequent meetings of the Council
 - Each subcommittee can either submit a small report or do a short presentation
 - Make this an appendix of the Plan

17

Questions?

18